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Health-related problems in adult cancer survivors: development and validation of the Cancer Survivor Core Set

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Abstract

Purpose Improved survival rates from cancer have increased the need to understand the health-related problems of cancer treatment. We aimed to develop and validate the “Cancer Survivor Core Set” representing the most relevant health-related problems in adult cancer survivors using the International Classification of Functioning, Disability, and Health (ICF).

Methods First, a Delphi study was conducted to select ICF categories representing the most relevant health-related problems. There were three Dutch expert panels, one each for lung, colorectal, and breast cancer. Each panel comprised lay experts and professionals. The experts reached within- and between-panel consensus in two rounds (≥ 70 % agreement). Second, a validation study was performed. Generic cancer survivorship questionnaires assessing health-related problems or quality of life among cancer survivors were selected. Items of selected questionnaires were linked to the best-fitting ICF category and to the selected ICF categories from the Delphi study, respectively.

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Results In total, 101 experts were included, of which 76 participated in both rounds, reaching consensus on 18 ICF categories. The Distress Thermometer and Problem List, the Impact of Cancer (v2), and the Quality of Life in Adult Cancer Survivors questionnaires were selected for the validation study, which led to the inclusion of one additional ICF category.

Conclusions The developed Cancer Survivor Core Set consisted of 19 ICF categories representing the most relevant health-related problems in adult cancer survivors: five from the “body functions and structures” component, eight from the “activities and participation” component, and six from the “environmental factors” component.

Highlights

- Many adult cancer survivors have persistent health-related problems.
- The Cancer Survivor Core Set was developed using the Delphi method.
- The patients’ perspectives were prioritized in this Delphi study
- Content validity was confirmed by validated cancer survivorship questionnaires.
- The Cancer Survivor Core Set may help optimize care for cancer survivors.

Keywords International Classification of Functioning, Disability, and Health · Disability evaluation · Delphi technique · Qualitative research · Survivors · Lung neoplasms · Colorectal neoplasms · Breast neoplasms

Introduction

Earlier detection of malignant conditions, improved diagnostics, and new treatment modalities mean that the number of

adult cancer survivors has increased substantially in most Western countries and is estimated to rise further in the near future [1–3].

Thus, the long-term effects of a cancer diagnosis are important to both research and clinical practice. Primary health-related problems include those related to the malignancy itself, the surgical treatment, and the toxicity of adjuvant therapy [4, 5]. Moreover, psychosocial symptoms are reported, such as fear of recurrence, disturbance of self-image, anxiety, depression, difficulties with return to work, and financial concerns [6–8].

It is important to understand and address the problems affecting adult cancer survivors [5, 9]. Therefore, screening instruments have been developed for specific health-related domains (e.g., health worries or body image concerns [10]) or subgroups of cancer survivors (e.g., prostate cancer survivors [11]). One such tool, the World Health Organization International Classification of Functioning, Disability, and Health (ICF), is a globally accepted classification that broadly represents human functioning, in a unified language. However, the ICF is cumbersome for use in daily practice, and derivatives have been developed for specific patient populations. These “core sets” list the ICF categories for specific conditions (e.g., breast cancer [12]) or settings (e.g., rehabilitation [13]).

To date, no core set has been established for the health-related problems of adult cancer survivors in general. Thus, we aimed to develop and validate the Cancer Survivor Core Set covering the most relevant health-related problems faced by cancer survivors.

Methods

Study design

To develop the Cancer Survivor Core Set, we performed a Delphi study [14] followed by a validation study [15]. In the Delphi study, we aimed to achieve consensus on the most relevant ICF categories for cancer survivors [16, 17] while prioritizing the patients’ perspective. In the validation study, we then assessed the content validity of the ICF categories using a linking procedure.

Delphi study

Composition of the expert panels

We defined adult cancer survivors as adults aged 18 years and over who had survived more than 1 year after diagnosis [18]. Panels were formed for lung, colorectal, and breast cancers. These cancers were selected based on current and projected rates of survivors adversely affected by health-related problems [19]; indeed, large increases in the numbers of survivors are anticipated [20].

There was a minimum of 25 survivorship experts per panel, with balanced proportions for three subpanels: experts by experience (lay experts), medical experts, and other healthcare workers (nine subpanels in total). We aimed to include lay experts who were able to reflect on the relevance of the ICF categories in adult cancer survivors based on more than their personal disease experience (a transcending view). Lay experts were selected through consultation with and advice from patient associations in the Netherlands.

Medical experts and other healthcare workers were selected through healthcare (or healthcare affiliated) organizations. Medical experts could be physicians or nurse practitioners. A physician could either be a medical oncologist, a surgical oncologist, a plastic surgeon, a radiation oncologist, or a radiologist. All healthcare workers had to be directly involved in the treatment of oncology patients or survivors. We invited potential experts to participate in the study by telephone or e-mail, and they provided written information. When lay experts judged themselves as being unable to have a transcending view, they were excluded from participation. Experts who provided informed consent were included in the Delphi study. According to our institutional review board, no approval was needed because this was a noninvasive study and not subject to the Dutch Medical Research Involving Human Subjects Act.

ICF categories

All ICF categories were divided into three components: “body functions and structures,” “activities and participation,” and “environmental factors.” The body functions and structures component covers functioning at the body level, while the activities and participation component covers an individual’s functioning. Environmental factors are factors possibly influencing functioning as either facilitators or barriers [21]. Each ICF component is further subdivided into three levels for more detail.

Delphi procedure

All 265 second-level ICF categories were used for item selection to avoid selection bias. ICF categories related to the body functions and structures component were only sent to the expert medical subpanels, because adequate evaluation required specific medical knowledge. Based on guidelines [17] and similar studies [22, 23], the Delphi study was required to consist of at least two rounds for consensus to exist.

During the first round, experts received the ICF categories with the corresponding description for coding, definition, inclusion, and exclusion. Experts were asked to evaluate the relevance of each ICF category (expressed by severity and/or frequency of a problem) for their cancer type. Response options were as follows: “not relevant” (score 1), “hardly

relevant” (score 2), “somewhat relevant” (score 3), “relevant” (score 4), “very relevant” (score 5), and “I cannot judge this ICF category” (score 0). Items selected in the first-round analysis were presented to each panel in a second round, when experts were asked to evaluate whether they agreed with inclusion or exclusion of ICF categories (see “Data analysis” section). Experts did not meet face-to-face, and they completed their assessments independently, either online or on paper. Participation could be refused at any point, and nonresponders received two reminders.

Data analysis

Data analysis was performed using IBM SPSS version 20.0 (IBM Corp., Armonk, NY, USA). The median scores, response frequencies, and percentages of panel responses were calculated per ICF category. Several analyses were performed after the first round to determine which ICF categories to include in the second round:

1. Median scores per subpanel (lay experts, medical experts, other healthcare workers) were calculated for each ICF category.
2. Median scores per panel (lung, colorectal, breast) were calculated for each ICF category. When the lay expert subpanel rated an ICF category as more relevant than the overall panel, the median score was adjusted to that of the lay expert subpanel.
3. An ICF category was included in the second Delphi round as a very relevant category if the median score of at least one of the three cancer panels was scored 5 and the score in the other two panels was ≥ 3 .
4. An ICF category was included in the second Delphi round as a relevant category if the median score of at least one of the three cancer panels scored 4, the other panels evaluated the ICF category with a score ≥ 3 , and no panel gave a score of 1.

After the second round, the content validity index (CVI) was assessed for each ICF category. This index is the proportion of respondents agreeing with the proposed relevance of the ICF categories [24]. If the subpanel of lay experts scored a higher CVI compared to others in their panel, the percentage was adjusted to the highest percentage. ICF categories scoring a CVI ≥ 0.70 in all cancer panels were included in the initial Cancer Survivor Core Set.

Validation study

Questionnaire selection

To detect cancer survivorship questionnaires that are widely used and sufficiently validated, a semistructured literature

review was performed in a single database using a limited number of search terms and strings. Eligible questionnaires were retrieved from the PubMed database (2000–2015) using MeSH terms in the search strings including the following: (“Survivors” [MeSH]) AND “Neoplasms” [MeSH]) AND “Surveys and Questionnaires” [MeSH]. We selected questionnaires that were developed by patient involvement at some stage. In addition, questionnaires were required to be (1) generic for cancer survivors; (2) assessing health-related problems or quality of life; (3) available online and in English; (4) have sufficient psychometric properties, illustrated by at least two validation studies; and (5) have demonstrated sufficient clinical utility in at least one study describing the use of the questionnaire in a cohort of cancer survivors. All eligible questionnaires were screened using these inclusion criteria.

Linking procedure

Two researchers with experience in oncology and working with the ICF (OG and KW) independently performed the linking procedure, according to the updated ICF linking rules [25]. Both researchers linked the items of the selected questionnaires to the most closely matching ICF category. Any discrepancies were discussed until consensus was reached, and a third independent researcher (AJB) was consulted if disagreements could not be resolved.

Items within questionnaires measuring positive changes after diagnosis (e.g., *Having had cancer has made me more willing to help others*) were excluded from the linking procedure, because the aim was to select health-related problems. The remaining questionnaire items could either be linked to an ICF category in the initial Core Set, be linked to an ICF category not in the initial Core Set (i.e., a newly identified ICF category), or not be linkable to any ICF category. It was possible to link more than one item to the same ICF category. If a new ICF category was identified on all questionnaires, it was added to the final version of the Cancer Survivor Core Set.

Results

Delphi procedure

Expert panels

In total, 441 potential experts were contacted, 101 of whom confirmed their expertise. Experts were evenly distributed across the panels and subpanels (Table 1). All experts completed the first round, and 76 experts (75 %) completed the second round assessment.

Table 1 Number and characteristics of experts across panels during the first (I) and second (II) Delphi round

	Lung cancer		Colorectal cancer		Breast cancer		Total expert panel	
	I	II	I	II	I	II	I	II
Subpanel—lay experts ^a								
Lay expert	13	10	10	8	21	12	44	30
Subpanel—medical experts								
Physician	3	2	9	5	5	5	17	12
Nurse practitioner	4	4	2	2	3	3	9	9
Subtotal	7	6	11	7	8	8	26	21
Subpanel—other healthcare workers								
Oncology nurse	9	7	4	3	3	3	16	13
Psychologist	1	—	—	—	1	1	2	2
Dietician	1	1	1	1	—	—	2	2
Social worker	1	1	1	1	2	1	4	3
Physical therapist	—	—	1	1	6	5	7	5
Subtotal	12	9	7	6	12	10	31	25
Total	32	25	28	21	41	30	101	76

A dash indicates no expert participating in that subpanel or the overall panel

I Delphi round 1, II Delphi round 2

^a Lay experts were experts by experience and defined as adults cancer survivors living more than 1 year after their diagnosis and selected based on their ability to give an overview on health-related problems among cancer survivors

ICF category sampling

The results of the ICF category selection process throughout the Delphi procedure are detailed in Table 2. After the first Delphi round, 21 ICF categories were evaluated as very relevant and 140 ICF categories were evaluated as relevant. In the second Delphi round, all selected ICF categories from the body functions and structures component were included, but two ICF categories from the activities and participation component (*d410 Changing basic body position; d530 Toileting*) and one ICF category from the environmental factors component (*e420 Individual attitudes of friends*) were eliminated. Participants agreed not to include any of the 140 ICF categories categorized as relevant in the second Delphi round. Due to the high level of consensus, there was no need for a third Delphi round. Thus, the initial Cancer Survivor Core Set comprised 18 ICF categories, of which 10 (56 %) were added by the lay expert subpanels.

Validation study

Selected questionnaires

In total, 15 questionnaires (Supplementary Table A) were retrieved, of which three met the inclusion criteria: the Quality of Life in Adult Cancer Survivors (QLACS) [10], the Dutch version of the Distress Thermometer and Problem List (DT/PL) [26, 27], and the Impact of Cancer version 2 (IOCv2) [28] (Table 3). These three questionnaires each included 47 items.

After exclusion of the positive items, we subjected 116 items to the linking procedure (39 items of the QLACS, 47 items of the DT/PL, and 30 items of the IOCv2).

Items linkable to the ICF categories in the initial Core Set

It was possible to link 70 items to ICF categories in the initial Core Set. We linked 32 items from the QLACS and 15 items from the DT/PL to eight ICF categories and 23 items from the IOCv2 to six ICF categories (Table 4).

Newly identified ICF categories

In total, 43 items were linked to 26 newly identified ICF categories: 6 items from the QLACS, 31 items from the DT/PL, and 6 items from the IOCv2. One new ICF category—*b130 Energy and drive functions*—was identified in each questionnaire and added to the initial Core Set. Another three ICF categories were identified in two questionnaires (*b126 Temperament and personality functions*, *b144 Memory Functions*, and *d845 Acquiring, keeping, and terminating a job*) but were not added to the core set. The remaining 22 ICF categories were identified by 25 items from the DT/PL and were excluded from further linking (Supplementary Table B).

Nonlinkable items

Three items (one per questionnaire) were not linkable to ICF categories. The items from the QLACS and DT/PL

Table 2 Number of selected categories per ICF component after each Delphi round

ICF component	Body functions and structures	Activities and participation	Environmental factors	Total
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Number of initial categories in the ICF	119 (45)	82 (31)	64 (24)	265 (100)
Delphi round I selection				
Very relevant	4 (19)	10 (48)	7 (33)	21 (100)
Relevant	55 (39)	53 (38)	32 (23)	140 (100)
Delphi round II selection	4 (22)	8 (44)	6 (33)	18 (100)

Percentages may not add up to 100 due to rounding. *Italic percentages displayed across rows*

ICF International Classification of Functioning, Disability, and Health

questionnaires focused on body image in cancer survivors, and the IOCv2 item involved an enumeration of related ongoing cancer- and treatment-related symptoms.

Unidentified ICF categories

Seven ICF categories from the initial Core Set were not covered by any of the questionnaire items: three from the

activities and participation component and four from the environmental factors component (Table 4).

Final Cancer Survivor Core Set

The final version of the Cancer Survivor Core Set consisted of 19 ICF categories: 5 (26 %) from the body functions and structures component, 8 (42 %) from the activities and

Table 3 Additional properties of the QLACS, DT/PL, and IOCv2 questionnaires

Questionnaire	Negative domains	Number of negative items	Positive domains	Number of positive items	Number of items to be linked
QLACS	Cancer specific	4	Cancer specific	4	39
	1. Appearance concerns	4	1. Benefits of cancer	4	
	2. Financial problems	4	Quality of life		
	3. Distress over recurrence	3	1. Positive feelings		
	4. Family-related distress	4			
	Quality of life	4			
	1. Negative feelings	4			
	2. Cognitive problems	4			
	3. Sexual problems	4			
	4. Physical pain	4			
	5. Fatigue				
DT/PL	6. Social avoidance				47
	Generic domains	7	None	0	
	1. Practical problems	3			
	2. Family/social problems	10			
	3. Emotional problems	2			
IOCv2	4. Religion/spiritual concerns	25			30
	5. Physical problems				
	Negative impact scale	3	Positive impact scale	4	
	1. Appearance concerns	3	1. Altruism and empathy	4	
	2. Body changes	7	2. Health awareness	5	
	3. Life interferences	7	3. Meaning of cancer	4	
	4. Worry	3	4. Positive self-evaluation		
	Additional subscales	7			
	1. Employment concerns				
	2. Relationship concerns				

All questionnaires consist of 47 items

QLACS Quality of Life in Adult Cancer Survivors questionnaire, *DT/PL* Dutch version of the Distress Thermometer and Problem List, *IOCv2* Impact of Cancer version 2 questionnaire

Table 4 Final version of the Cancer Survivor Core Set with content validity percentages per cancer panel and association with the QLACS, DT/PL, and IOCv2 questionnaires

ICF category		Lung cancer (%) ^a	Colorectal cancer (%) ^a	Breast cancer (%) ^a	QLACS ^b <i>k</i> = 39	DT/PL ^b <i>k</i> = 47	IOCv2 ^b <i>k</i> = 30
Body functions and structures							
Mental functions							
b130	Energy and drive functions ^c	33	57	50	—	—	—
b140	Attention functions	83	86	75	2	1	—
b152	Emotional functions	100	100	100	13	6	11
Sensory functions and pain							
b280	Sensation of pain	100	71	100	4	1	—
Genitourinary and reproductive functions							
b640	Sexual functions	83	86	100	4	1	—
Activities and participation							
Learning and applying knowledge							
d166	Reading ^d	68 (70)	76	70	—	—	—
d177	Making decisions	88	81	83	—	—	1
General tasks and demands							
d240	Handling stress and other psychological demands	100	95	93	—	—	—
Mobility							
d475	Driving ^d	84	71	67 (82)	—	—	—
Self-care							
d570	Looking after one's health ^d	100	86	83	—	—	1
Interpersonal interactions and relationships							
d710	Basic interpersonal interactions ^d	88	81	83	3	—	1
d720	Complex interpersonal interactions ^d	76	86	80	2	3	8
Major life areas							
d870	Economic self-sufficiency ^d	100	86	83	3	1	—
Environmental factors							
Products and technology							
e310	Immediate family	100	95	100	—	1	—
e320	Friends	100	91	97	—	—	—
e355	Health professionals	96	100	90	—	—	—
Attitudes							
e410	Individual attitudes of immediate family members ^d	64 (70)	71	77	—	—	—
Services, systems, and policies							
e570	Social security series, systems, and policies ^d	88	86	97	—	—	—
e580	Health services, systems, and policies ^d	96	91	100	1	1	1
Items linked to other ICF categories	—	—	—	6	5	7	
Nonlinkable items	—	—	—	1	1	1	
Short-term items	—	—	—	0	26	0	

^a Percentages displayed between brackets depict the CVI of only the lay expert subpanel^b Number of linked items (*k*=) is displayed. The digit indicates the number of items addressing the respective ICF category, while a dash indicates that this ICF category was not covered by the respective questionnaire^c This ICF category was added after establishing content validity by the described linking procedure. The number of items linked to this ICF category is included under "Items linked to other categories"^d This ICF category was added by the lay expert subpanel throughout the Delphi study

participation component, and 6 (32 %) from the environmental factors component.

Discussion

In the current study, we aimed to develop and validate a core set representing the most relevant health-related problems of adults surviving cancer for more than 1 year after diagnosis. This led to the creation of the Cancer Survivor Core Set, consisting of 19 ICF categories.

To the best of our knowledge, no other study has used the ICF to develop a core set generic for cancer survivors. The selected ICF categories in our core set represent the most relevant health-related problems of cancer survivors from a broad perspective. Moreover, we explicitly prioritized the patients' perspective, which resulted in the addition of several ICF categories in the Delphi study. Although we realize that the cancer survivorship experience most likely consists of a balance between positive and negative impacts, we have decided to only identify the health-related problems in cancer survivors in the current study since we felt that these may significantly hamper a persons' functioning and require adequate attention from healthcare providers.

Only one ICF category was added to the core set in the validation study, indicating that the experts selected a credible sample of health-related problems experienced by cancer survivors. In addition, it was possible to link 70 questionnaire items to the initial Core Set, further supporting this notion. In contrast, the fact that seven ICF categories in the initial Core Set were not covered by existing questionnaire items may indicate that important issues of cancer survivorship are not always identified by current questionnaires.

Compared with earlier studies in which core sets were developed, we selected a considerably smaller number of ICF categories [12, 22, 23, 29]. A possible reason for this is that we aimed to identify the most relevant ICF categories for a broad yet concise reflection of relevant health problems. Consequently, we applied strict inclusion criteria for ICF categories to be eligible for inclusion in our core set. Moreover, the ICF categories were selected from the second level of detail (e.g., *B152 Emotional problems*), making them primarily relevant for identification. In clinical practice, further elaboration of an identified health-related problem will likely be needed.

A strength of this study is that we did not preselect ICF categories. Moreover, we included a large, varied panel of experts, strengthening the validity of our results. The fact that written assessments were completed independently and anonymously ensured that experts could not influence each other [17]. The experts achieved a high level of consensus during the Delphi procedure by the second round. Because of this high level of consensus, there was no need for a third round.

A potential limitation is the dropout rate between Delphi rounds (25 %), which was unexpected and higher than that in similar studies [22, 23, 30, 31]. A possible explanation is that some experts, mainly lay experts, regarded the language in the ICF as too formal. However, we provided each ICF category with the ICF definition and the inclusion and exclusion criteria. In addition, we believe that this loss of experts did not affect the overall diversity and proportions within and between the cancer panels in the second round.

Another limitation is that our choice of panels may preclude generalizability to other cancers. However, limitation to the three cancers was based on expected prevalence rates and likely similarities in disease course [19].

In conclusion, with the continued growth in the number of adult cancer survivors, the Cancer Survivor Core Set offers a valid yet concise reflection of the most relevant health-related problems in a general population of cancer survivors. However, although our results are promising, future studies are needed to confirm the generalizability of the Cancer Survivor Core Set in other settings and groups. The core set may be operationalized into a screening instrument to assess persistent health-related problems. Hereafter, targeted interventions may contribute to optimal and integrated care for adult cancer survivors.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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